

# **Respite Services for Caregivers**

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## EXECUTIVE SUMMARY

This review focuses on the available evidence of the effectiveness of respite services in alleviating the strain on caregivers of older people. Respite services have been defined broadly to include all those programs that provide temporary relief to family caregivers. These services include in-home respite, adult day care, overnight respite, and mixed programs that offer two or more types of respite. To assess the effects of respite programs, four possible outcomes have been considered: (1) benefits to the caregiver; (2) benefits to the older care recipient; (3) reducing or delaying institutionalization; and (4) cost savings. The type of care recipients, whether they are cognitively intact, impaired, or are mixed, has also been taken into account in analyzing outcomes when that has been possible.

The main findings from a review of the current empirical literature are:

1. Despite the overall importance of respite in community long-term care, there have been very few systematic evaluations of these programs. Many of the available studies are flawed due to small sample size, poor measurement, lack of an appropriate control group, or inadequate delivery of respite services.
2. Benefits to caregivers are related to the amount of respite services delivered. Studies in which only small amounts of respite were provided reported little or no benefits to caregivers. Studies in which sufficient amounts of respite were utilized show a reduction in care-related stress.
3. Benefits have been demonstrated most clearly for caregivers using adult day care. Findings for in-home respite use are generally positive but the research is more limited. Virtually no evidence is available concerning benefits of overnight respite.
4. Many of the studies with disappointing outcomes involved case or care management to increase respite use. In these studies, case management produced only modest increases in respite use compared to control groups, and little or no improvement among caregivers.
5. A major theme raised repeatedly in these studies is that many caregivers do not use respite services, use only small amounts of respite, or use it only very late in the care process. Little is known about the reasons caregivers make these choices, or if current services fail to meet the perceived needs of this group of caregivers. Overly bureaucratic procedures and cost have been identified in some studies as factors related to low use, though low rates of use have also been found when these barriers are reduced.
6. Evidence of benefits for care receivers is very limited but the available studies suggest that respite has benign, or in the case of adult day care, possible positive effects.
7. There is little evidence that respite services delay institutionalization or produce cost-savings. In part that is due to caregivers using respite late in the care process, and in part because respite may not by itself, address the major causes of placement. Adult day care and overnight respite may actually facilitate placement in some cases by giving caregivers the emotional distance necessary to let go.

8. Little is known about how the benefits of respite may differ for different groups of users (people with dementia, people who are cognitively intact) and for different caregivers (spouses, daughters, other caregivers).
9. Evaluation of respite services and identification of measurable outcomes must be viewed as at an early stage in its development. Stronger research methods need to be coupled with promising service delivery models to obtain better information about the advantages and disadvantages of respite.
10. Future studies of respite need to be guided by theory that identifies those aspects of the stress process likely to be affected by respite use. This approach will lead to better choices of outcome measures and a better understanding of what specific changes result from respite use.

Respite services have long been regarded as a promising tool for lowering the burden on family caregivers, thereby helping them care for a disabled elder in the community for a longer period of time. These services take different forms: in-home respite, adult day care, and overnight respite, but the primary objective is the same—providing temporary relief to the primary family caregiver. This review examines what is currently known about the effectiveness of respite programs and the practice implications for the aging network, as well as questions that remain to be addressed.

There is surprisingly little research on the effectiveness of respite services. Only a handful of studies using appropriate control groups have been conducted. While it may seem obvious that respite services *should* be effective in lowering stress on caregivers, the findings are mixed. Some studies show little or no benefit, while other studies show moderate benefits. The value of careful research is to identify under what circumstance respite is effective. There needs to be consideration of what type of programs are more effective, how much respite needs to be provided, and what specific benefits result. These types of analyses would provide a valuable tool for planning services and for providing a strong rationale for better funding for these services.

## A FRAMEWORK FOR EXAMINING THE EFFECTIVENESS OF RESPITE

The examination of the effectiveness of respite services can be organized along three dimensions (see *Exhibit 1*): type of respite service; type of benefits; and type of care recipient.

**Exhibit 1**  
**Framework for Evaluating Respite Services**

Type of Respite	Type of Benefit	Type of Care Recipient
In-Home Respite	To Caregivers	Dementia Patients
Adult Day Care	To Patients	Mixed Samples – Dementia and Non-Dementia
Overnight Respite	Preventing Nursing Home Placement	
Multicomponent Programs	Cost-Effectiveness	

### Type of Respite Services

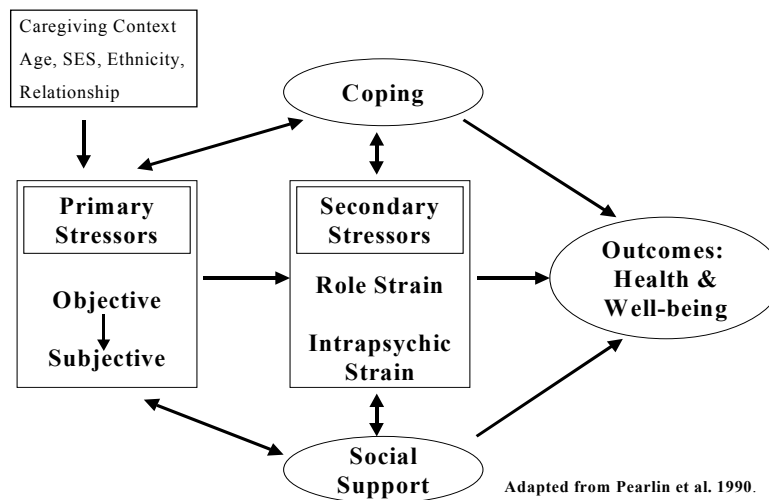
Although respite services have a common core of providing relief to family caregivers, it is reasonable to expect that different types of respite may have different benefits. For the purposes of this review, we examine benefits within service type for in-home respite, adult day care, overnight respite, and, finally, multicomponent programs in which respite is one feature, or where caregivers can use different types of respite.

### Type of Benefit

Implicit in its name, respite care targets family caregivers. It is they who are expected to experience “respite” from the break they receive from caregiving activities. But what exactly is the nature of that benefit?

As research on family caregiving has gained in sophistication, it has become increasingly obvious that we cannot speak of caregiver burden or stress as if they were single entities. Rather, caregiving involves multiple stressors that can affect the caregiver in many different ways (Aneshensel et al., 1995). One such model is presented in *Exhibit 2*.

## Exhibit 2 The Stress Process Model of Caregiving



This model, developed from the longitudinal study of Leonard Pearlin and his colleagues (Pearlin et al., 1990; Aneshensel et al., 1995), identifies three main components of the stress process: (1) primary stressors, (2) secondary stressors, and (3) outcomes. Primary objective stressors are the disease-related changes in functioning and behavior that place care demands on the family. These demands have an immediate impact on caregivers, called primary subjective stressors. Caregivers may have feelings of overload (having more to do than they can manage) or strain (performing tasks that are emotionally difficult to manage), or may experience role captivity (feeling trapped by the demands of care). Primary stressors may proliferate or spillover to other areas of a caregiver's life, leading to what Pearlin and associates call secondary stressors. Secondary stressors are no less important than primary stressors, but are not intrinsic to caregiving; that is, some people may experience these changes and others will not. Examples of secondary stressors include work-caregiving strain, family-caregiving strain, and financial strain. There can also be secondary subjective stressors, such as loss of self-esteem, and a loss of identity. Finally, the combination of primary and secondary stressors leads to outcomes, which involve emotional and physical well being, as well as the ability of caregivers to maintain the person at home.

The value of this and other similar models (see Schulz, 2000) is that they can guide the development of evaluations of respite interventions. It is not likely that any intervention will affect all aspects of the stress process. Rather, the intervention is likely to have a direct impact on some areas, and an indirect or no effect on others. As an example, adult day care provides a reliable break for caregivers from ongoing supervision and care. It may therefore have its greatest impact on feelings of overload and strain (primary subjective stressors), but a less direct effect on emotional well being. By focusing evaluations in this specific way, it becomes more likely to identify the effects of a particular intervention. Research on respite and other caregiver interventions is still in a formative stage, and generally has not used this type of focused approach. Some of the limitations in current studies may be due to that fact. As we look toward

obtaining better evidence about the effects of respite, consideration of this issue will enhance future studies and will help program staff articulate what it is that their intervention is able to do.

Another factor to be considered in the evaluation of respite services in relation to type of benefit is the perspective of the client or patient. This perspective has been missing from most respite research. Yet it is clear that the acceptability of services to dependent elders is critical to their success. When an older person refuses help, or creates difficulties for caregivers for having arranged for help, then the caregiver will not experience much relief. Beyond acceptability, we also need to look at whether clients receive any benefits from the service, or at least do not deteriorate. For example, one frequently discussed issue is if people with dementia experience a worsening of cognitive or behavioral symptoms when using overnight respite, because of being placed in a foreign setting. The finding that a patient worsened even though the caregiver benefited from a particular service would temper enthusiasm for that program. This is a possible scenario when considering any intervention with a frail older person.

A third factor of benefit is whether respite reduces or delays nursing home placement. In examining this benefit, however, we need to clarify in whose interest is it to delay placement. Aneshensel and colleagues (1995) suggest that the interests of caregivers and dementia patients diverge on placement. Placement that is earlier in the course of the disease benefits caregivers because they are no longer facing around the clock stress yet individuals with dementia benefit in most cases from staying at home longer. Placement takes them out of a familiar setting and exposes them a higher than expected risk of mortality in the immediate post-placement period. It is also likely that family caregivers differ in their views of placement. Many families want to keep a relative at home for as long as possible, and probably would use respite services toward that end. Other families may not want to delay placement, but use respite to be able to get by until they feel the time is right for placement. Adult day care and overnight respite may even serve as a trial placement for some caregivers.

Delaying placement benefits the state or general public most by reducing the costs of institutionalization, especially if the period of time in which individuals must use Medicaid to pay for long-term care is reduced. There have been a few studies to determine if respite results in cost-savings by reducing use of more expensive services (nursing homes, hospitalization). Cost savings are an important consideration and can support the argument for using public funds to pay for respite services. But cost savings should not be the overriding concern, compared to the effects on caregivers and patients. A related strategy is the cost-effectiveness of respite, that is, what costs are associated with particular benefits to the caregiver or client.

### **Type of Care Recipient**

The final consideration for evaluating respite services is the type of care recipient. Dementia places special challenges on families and on respite workers (Birkel, 1987; Ory, Hoffman, Yee, Tennstedt, and Schulz, 1999). Stress on families is likely to be greater when dementia is present as will be the potential problems associated with using services. For that reason, an analytic consideration is if the clients of a particular study represent a mixed dependent population that includes people with dementia and those without, or a sample of people only with dementia. (I use the term dementia throughout to denote cognitive decline due to Alzheimer's disease or other neurodegenerative illnesses. There is little evidence that

response to respite differs by type of dementing disorder, nor have most field studies had the resources to differentiate type of illness).

## **EVIDENCE FOR THE EFFECTIVENESS OF RESPITE SERVICES**

We now turn to examine the evidence for effectiveness of respite services. Following the framework shown in *Exhibit 1*, the findings are grouped by the type of respite service: in-home respite, adult day services, overnight respite, and multidimensional or mixed programs. Within each section, there is consideration of benefits to caregivers, to patients, effects on institutionalization, and any cost data that may be available. Finally, it is noted whether the sample was mixed or comprised only of people with dementia.

### **In-Home Respite**

In-home respite is the type of help most widely used by family caregivers (Caserta et al., 1987). Caregivers often report a preference for this type of help. Although the studies of in-home respite are limited, the findings are generally positive. One problem in comparing the results of the various studies, however, is the definition of in-home respite can vary. In some instances, respite was primarily companionship, and the worker did not perform other care activities, such as helping with ADLs. In other instances, the primary function appears to have been assisting with ADLs and other care tasks. The extent to which respite is acceptable to caregiver and older person, as well as any benefits that might accrue, could differ depending on how the service is structured.

#### ***Benefits to Caregivers***

Overall, there is limited, but positive evidence of benefits for caregivers. Receiving in-home respite has been found to be associated with improved mood (Curran, 1995; Gwyther, 1989) and reduced emotional distress (Harper et al., 1993). Deimling (1992) examined changes over time in a sample of caregivers of people with dementia, and reported that respite stabilized feelings of strain and depression for caregivers of people with declining cognitive abilities, and improved mood among those caregivers whose relative's cognitive functioning was relatively stable during the period under investigation.

In one of the most sophisticated analyses of the effects of respite, Bass, Noelker and Rechlin (1996) found that service use had a moderating effect on depression and health for a sample of caregivers of dependent elders (including dementia and non-dementia). Specifically, a moderating effect means that caregivers experiencing higher stress had greater benefits from service use. The services in this study were not explicitly respite, but included assistance with personal and instrumental activities of daily living.

An important issue to consider is how respite might reduce burden on family caregivers. Toward that end, Berry, Zarit and Rabatin (1991) looked at the effects of in-home respite and adult day care on the time that caregivers of dementia patients spent in various care-related activities. Caregivers who had in-home help experienced a decrease in the amount of time they had to spend helping their relative with activities of daily living while those using adult day care had a slight increase. The reason for this difference was that the in-home respite worker assisted with ADLs, while caregivers using adult day care managed all the ADLs themselves. They often



had to assist patients with bathing and dressing under some time pressure because they had to get the patient ready for day care. Interestingly, the in-home service was supposed to involve only respite, but families and workers had obviously negotiated a different type of involvement. Caregivers receiving in-home care were very satisfied with the help they received, and would have liked increased assistance (Berry et al., 1991; MaloneBeach, Zarit and Spore, 1992). These findings suggest that caregivers who are having difficulty managing ADLs by themselves might benefit differentially from in-home help that includes ADL assistance.

Despite the generally positive findings for in-home respite, some caregivers reported problems with this service (MaloneBeach et al., 1992). Families described some in-home staff as poorly trained and unreliable and commented that workers sometimes fail to show up at designated times. Families also expressed a preference to have say over who comes into the home. They did not like agency policies of sending whoever is available, as opposed to having a worker they like do most or all of the visits (Montgomery, 1995). They also found that some agencies would dictate the hours or days of service, without input from the caregiver.

### ***Benefits to the Care Recipient***

There are no studies to date that examine benefits of respite to the care recipient, or even the acceptability of this type of help. Anecdotally, at least some older people are reluctant to let workers into the home to assist with any activities, including respite. Gaining access and acceptance are clearly important issues that warrant further study.

### ***Benefits in Delaying Nursing Home Placement***

The evidence that in-home respite affects institutionalization is limited and inconsistent. Two studies were identified that addressed this question. Each of these studies used an enhanced program of in-home help. The most positive benefits were reported in a Dutch study by Vernooj-Dassen and colleagues (Vernooj-Dassen, Huygen, Felling, & Persoon, 1995) who used home health aides to deliver both emotional and practical support to family caregivers of people with dementia. They reported a reduction in placement in the treatment group compared to control group. This is, of course, a more intensive intervention than in-home respite usually involves.

Another intensive intervention was conducted by Mohide et al (1990), who used a nurse to provide four hours of weekly in-home respite. The nurse also worked with the caregiver around stress and health issues. The treatment group showed a slight reduction in institutionalization compared to controls, though there was high attrition in both groups due to mortality.

### ***Benefits in Cost-Effectiveness***

There have been no cost analyses specifically of in-home respite.

## **Adult Day Services (ADS)**

### ***Benefits to Caregivers***

The main study of adult day services (ADS) to date was conducted by several of my colleagues and myself (Zarit et al., 1998). The goal of the study was to examine the benefits of adequate amounts of ADS for family caregivers of people with dementia, compared to a control group not using ADS or other respite services. The research developed in part in response to findings from an earlier, major study of respite (Lawton et al., 1989a and b). In the earlier study, people who were assigned to a treatment group involving case management to encourage the use of either in-home respite or ADS, differed little in outcomes compared to a control group. In analyzing the findings from that study, we felt that a major limitation was that people in the treatment group used very low levels of respite (averaging less than one day of ADS and 5 hours of in-home respite per month). Compounding the problem further, the control group actually used small amounts of respite services as well.

In our study, we established a minimum amount of use of ADS necessary for therapeutic benefits for caregivers. This amount, two days a week for a period of three months, was established after consultation with ADS staff and our collaborators at the New Jersey Department of Health and Senior Services. Caregivers not using this minimum amount of ADS were dropped from the comparisons. This approach of setting a therapeutic minimum is similar to considering dosage in a drug study. Just as we would not judge the efficacy of a medication based on a subtherapeutic dosage, we should not evaluate respite services when insufficient help is being provided.

Random assignment into treatment and control conditions was not possible, as is often the case in this type of study (See Zarit & Leitsch, 2001, for a discussion of research designs in field studies). As an alternative, the study used a quasi-experimental design of two comparable groups, one of which received the treatment and one which did not. The treatment group consisted of caregivers of people with dementia who were enrolling a relative into an ADS program in New Jersey. The control group was recruited from a region in another state (northeastern Ohio) where there was limited availability of ADS for dementia. Going to a state where day care options for dementia was limited made it possible to avoid the problem of having caregivers who selected into the treatment and control group. To assure comparability, however, participants in the control condition had to indicate a willingness to use ADS. If a caregiver in the control group initiated ADS during the course of the study, he/she was dropped from the comparison.

The results were analyzed for two sets of measures. The first set, primary appraisals of stress, was designed to assess the immediate impact of care routines on the time, effort and energy of caregivers. The measures were overload, strain and role captivity. We expected that ADS would have the greatest impact on these measures, since caregivers would experience partial relief from providing care and from the associated time pressures. The second set of measures focused on well being, including depressive symptoms, anger and positive emotions. We expected less change on these measures since the use of ADS does not directly affect caregivers' well being. After three months, caregivers receiving ADS had significantly lower scores on two of three primary appraisals of stress measures—overload and strain. This was the

expected result. Unexpectedly, they also had significantly lower scores on two of the well-being measures—depressive symptoms and anger. Thus, the benefits of ADS for caregivers were more far-reaching than anticipated. Caregivers were assessed again after one year, and benefits were still evident. At the one-year interval, caregivers using ADS had lower feelings of overload and lower depressive symptoms than controls.

In addition to these findings, we examined caregivers' reports of satisfaction and perceived benefits and drawbacks of ADS (Jarrott et al., 1999). Reports of satisfaction with all aspects of the program were high, except for cost and transportation. Even in those areas, a majority of respondents indicated they were satisfied. Few drawbacks were reported and only a few caregivers reported difficulties getting care recipients ready to go to ADS or other problems related to ADS use.

The main limitation of ADS that emerged in this study was that many people used it briefly. Almost thirty percent of the sample used ADS less than the three-month minimum, and some people used it only for a few days. Two main factors were related to brief use (see Zarit et al., 1999). First, many caregivers waited too long to use ADS, and their relative was too frail to benefit. In many instances, stopping use was precipitated by an illness in the patient, which then led to placement. The second factor was that people caring for a husband or wife were more likely to use ADS for a brief period of time. These caregivers may have experienced difficulties turning the care over to someone else and/or encountered more resistance to going to ADS from their relative.

Other studies confirm the direction of these findings. In a Canadian study, Gottlieb and Johnson (1995; 2000) reported reductions in anxiety and perceived stress, as well as high levels of satisfaction for caregivers of people with dementia who used ADS. They also found comparable rates of discontinuing ADS to the Zarit et al. (1998) study. Gottlieb and Johnson (2000) also conducted a qualitative analysis of benefits reported by family caregivers. They found responses fell into three categories. First, caregivers reported a reduction in stress and vigilance from not having the patient around them all the time. Second, they felt a sense of freedom from the ongoing demands of care and reported they could do what they liked for the period of time the patient was in the ADS program. Third, caregivers were pleased because their relatives liked the ADS program and were well cared for in the program. Another Canadian study found an increase in life satisfaction among caregivers compared to a control group not using ADS (Strain et al., 1988). In a Swedish study, Wimo and colleagues (1990) reported an increase in well being among caregivers of people with dementia after 6 months of ADS use.

A recent report by Quayhagen and colleagues (2000) compared four treatments for patients with early stage dementia and their caregivers: cognitive stimulation, dyadic counseling, dual supportive seminar and early stage day care. There was also a wait list control condition. Findings were examined after three months. Compared to the other treatments, caregivers in the day care and dyadic counseling conditions had lower feelings of hostility and used more positive coping strategies. Caregivers whose relative received cognitive stimulation reported lower depression after three months, compared to the other conditions.

In summary, there is clear evidence of benefits of ADS to caregivers, though these findings must be qualified by the high attrition from programs in the first months of use.

### ***Benefits to Care Recipients with Dementia***

Although there are many comments in the literature on the benefits of ADS for participants, there is little systematic research on this issue. In an early report, Jones and Munbodh (1982) found improvements in mood and life satisfaction among ADS users and decreased cognitive problems. Strain et al. (1989) also reported increased life satisfaction in a sample of people with and without dementia. Levin and her colleagues (1989) reported that family caregivers felt that their relative benefited from the social contact and interactions. Wimo and colleagues (1993) found improvement in well being among people with dementia using ADS, but no evidence of effects on behavior or ADL functioning.

Drawing on qualitative reports from family caregivers, Gottlieb and Johnson (1995) found evidence of improvement in mood and increased participation in activities among clients of ADS suffering from dementia. Many caregivers indicated their relative looked forward to going to ADS and benefited from the change in scene. Jarrott and colleagues (1999) also drew upon reports by family caregivers of both benefits and drawbacks experienced by ADS clients with dementia. After using ADS for three months, caregivers indicated that there were improvements in clients' behavior, including decreases in agitation and sleep problems after attending ADS. Only a small proportion of caregivers reported problems around ADS use, such as difficulty getting the client ready in the morning or difficulties around drop off and pick up. It should be noted, however, that these reports came from families who had been using ADS on a regular basis, and did not include caregivers that used ADS for only a brief period of time.

The study by Quayhagen and colleagues (2000) described above that focused on people with early Alzheimer's disease and their caregivers found improvements in patients' cognitive functioning associated with receiving cognitive stimulation compared to the other treatments, including early stage day care. There were no differences in rates of behavior problems among the treatments. Patients' mood and quality of life were not examined.

In summary, there is mainly anecdotal evidence of benefits to clients. Although the results are promising, more systematic study is needed, including more careful analysis of the reasons why some caregivers and clients use ADS for only a brief period of time.

### ***Benefits in Delaying Nursing Home Placement***

There appears to be little evidence that ADS reduces or delays placement (Ballinger, 1984; Greene & Timbury, 1979; Hedrick et al., 1993; Weissert et al., 1980). In an analysis of placement rates, Gottlieb and Johnson (2000) suggest that for people with dementia the decision to use ADS comes late in the disease, and probably reflects that caregivers are taking a preliminary step toward placement. They found that 26% of ADS users had been placed within 6 months and 44% within 12 months. Similarly, in our study of ADS use (see Zarit et al., 1998; 1999), we found 11% had placed a relative within 3 months, 37% within one year, and 63% within two years. On the other hand, a majority of long-term users of ADS felt that they had been able to delay placement because of the help they received.

These findings suggest a mismatch between objectives of policymakers and program administrators, on the one hand, and families on the other hand. While the former view ADS as

a way of delaying placement, many caregivers use ADS at a time when placement has become increasingly likely. Some may even use ADS as a trial placement. The success they experience using ADS helps them take the next step to placement.

### ***Benefits in Cost-Effectiveness***

A few studies have examined the costs and the cost-effectiveness of ADS. Hedrick and colleagues (1993) found that ADS increased costs for patient care, because there was no savings from decreased hospital and/or nursing home use. In a small study in Sweden, Wimo and associates (1990) reported a cost-effectiveness of ADS, that is, that the cost of one day of ADS (about \$10) was associated with a 54% improvement in well being. Using a similar approach, Gaugler and Zarit (in press) estimated daily costs to the caregiver and to the public (in the form of subsidies for ADS) for reducing overload and depression. Daily costs for caregivers were \$6.38 for overload and \$2.90 for depression after three months. Public costs were similar showing \$5.46 for overload and \$2.47 for depression. Results after one year of ADS use showed a reduction in the costs of producing changes in overload and depression. It should be noted that no cost savings were associated with ADS, since there was no reduction of nursing home use compared to a control group.

### **Overnight Respite**

Overnight respite is the least available of respite services and has been the least studied type of respite. There have been few systematic demonstrations of overnight respite, and it has not been part of a major policy initiative, at least in the United States. The availability of overnight respite appears to be largely a matter of local factors, and the ad hoc basis of many programs has precluded careful evaluation.

### ***Benefits to Caregivers***

Most studies of overnight respite have found that benefits for caregivers are transitory (Adler et al., 1993; Burdz et al., 1988; Larkin & Hopcroft, 1993; Scharlach & Frenzel, 1986). Caregivers experienced relief during the period in which overnight care was offered, but returned to prior stress levels after the person returned home. One study, however, failed to find even temporary benefits (Homer & Gilleard, 1994). These transitory benefits are not surprising, since caregivers resume their regular routines once overnight respite comes to an end.

### ***Benefits to Care Recipients***

It would be expected that some people would have trouble adjusting to a temporary placement, especially those suffering from dementia. As a reaction to the strangeness of the facility and routines, they would show an increase of behavioral problems. This upset might also carry over when they return home. The one study to date which explored this issue, however, found the opposite effect (Burdz et al., 1988). In a sample that included people with and without dementia, a two-week stay in a nursing home was associated with a decrease in behavior problems and improved ADL performance after the placement, while a control group showed worsening in those areas. These results suggest that a therapeutically-oriented program of temporary institutionalization might have benefits for participants. Given the problems typically

associated with moves, especially for people with dementia, there should be more careful study of this issue.

### ***Benefits in Delaying Nursing Home Placement***

The one study to comment on the effect of overnight respite in delaying institutionalization (Scharlach & Frenzel, 1986), found that overnight respite helped families make the transition to placement rather than delaying placement. This may have been an unusual sample, since it involved veterans who were already on a waiting list for placement. From this study we can conclude that once families make the decision to place, overnight respite does not change their mind.

### ***Benefits in Cost-Effectiveness***

No studies have examined costs or cost-effectiveness of overnight respite

## **Multicomponent Studies**

The major initiatives in community-based respite services have been multicomponent programs. The following is a review of three of these demonstrations (Lawton et al., 1989; Montgomery & Borgatta, 1989; Newcomer et al., 1999a and b; see also Kosloski & Montgomery, 1993). In these programs, participants may have used different types of respite (in-home, day care, overnight), and there may have been other interventions as well. As a result, it can be difficult to attribute findings from these studies to a particular type of respite, or, in some cases, to respite as opposed to other components of the intervention. Actual utilization of services was also a major issue in each program.

In the study by Lawton and colleagues (1989) caregivers of people with dementia who volunteered for a research project were randomly assigned to a case manager or a control group. For people in the experimental group, the case manager tried to match them with appropriate respite services. A small amount of financial assistance was available based on need. Participants in the control condition received a list of available services in the community. The results showed only small benefits for the treatment group. There was little difference in well being or subjective burden, but the treatment group showed a small delay in nursing home placement (22 days). Although this study was interpreted by some observers (e.g., Callahan, 1989) as a failure of respite, the main factor related to lack of positive findings was that the treatment group used low levels of respite. As noted earlier, average use was less than one day of ADS and 5 hours on in-home respite per month. Further compounding the problem, the control subjects used some respite during the course of the evaluation. Rather than suggesting a failure of respite, the findings indicate that case management does not necessarily increase use of respite services. It should also be noted that caregivers did not join the study because they were seeking respite, but in response to general outreach for research on caregiving. Since some participants may not have wanted or needed respite at the outset, that would further decrease use and subsequent benefits from respite.

The second project was conducted by Montgomery and her colleagues (Montgomery & Borgatta, 1989; Kosloski & Montgomery, 1995). Participants were caregivers of people with varied disabilities. They were randomly assigned to one of 5 treatment groups or a control

condition. The treatments were: (1) eligible for all services; (2) eligible for family consultation, caregiver seminars and support groups; (3) eligible for caregiver seminars and support groups; (4) eligible for family consultation services; and (5) eligible for respite services. A federal waiver was used to help pay for respite services. The control group was assessed at two points in time, but received no other services. The results showed a reduction in objective and subjective burden for all treatment groups, compared to the control condition. Placement appeared delayed among adult children who were caregivers but increased for spouses. Montgomery and Borgatta (1989) also noted that many caregivers used little or no services, despite efforts to make respite care affordable. A re-analysis focusing on the two groups that received respite (Group 1: Eligible for all services and Group 5: Eligible for respite services) found that people using greater amounts of respite had a lower likelihood of placing a relative. No outcomes were reported for the care receiver.

The third project was the Medicare Alzheimer's Disease Demonstration Evaluation (MADDE), which was evaluated by Newcomer and his colleagues (Newcomer et al., 1999a and b; Newcomer, Fox, & Harrington, 2001). This multisite trial assigned caregivers of people with dementia into a multicomponent treatment condition which included case management and financial assistance for service use which could be used for a variety of community-based services, including in-home respite and adult day services. There were no differences in caregiver stress, depression or burden. Medicare expenditures were somewhat reduced. There were, however, no differences in institutionalization rates. These results are again confounded by the fact that the control group used nearly as much respite services as the treatment group (73 days for controls, compared to 78 for the treatment group). Consistent with the Lawton et al. (1989) findings, the results suggest that case management may not increase respite use much above what people are able to obtain on their own. Again, no benefits or drawbacks were noted for the care recipients.

These three studies illustrate the difficulty in evaluating the effects of respite care. Each of the projects involves several components, only one of which was respite. In addition, the use of respite was limited. The relatively modest findings of these projects may be due to the diffuse nature of the interventions, the fact that caregivers received small (or in some case, no) amounts of help, and problems in the research design that failed to assure a meaningful difference between treatment and control groups. The primary message from these studies is that small amounts of respite make little or no difference.

## **INTEGRATION OF FINDINGS**

There are six main points that emerge from these studies. First, respite services show benefits for caregivers when provided in sufficient amounts. Caregivers experience a cascade of stressful events that proliferate through every area of their lives. Given the enormity of the tasks they face, it is understandable that a few hours of respite a month would make very little difference. Regular and reliable respite care provided twice a week or more reduces care-related strain and improves well being.

Besides the quantity of respite, there also needs to be consideration of the quality of respite. Caregivers have reported some problems in delivery of in-home respite, including poorly trained and unreliable home support, and difficulties obtaining help during the hours they need it most (MaloneBeach, Zarit, & Spore, 1992). They also prefer working with one person,

not having different people come to the home each time. It is possible that re-design of in-home respite so that it addresses these preferences of caregivers would result in better use and more positive outcomes. Likewise with adult day services, there has not been much focus on the quality of the programs, although caregivers report few difficulties or concerns about quality (Jarrott et al., 1999).

Second, a major issue in the delivery of respite services is that many people do not use these services, use small amounts of respite or use them for only a short period of time. Reviewing the available evidence, Gottlieb and Johnson (2000) found that between 26% and 44% of caregivers had stopped using ADS within a six-month period. Zarit et al. (1998; 1999) reported that 30% of caregivers had stopped using ADS by three months, some of whom used very low levels of service in the first place. People stop using in-home respite at similar rates (Cox, 1997). Many of these caregivers placed their relative when they stopped using ADS or in-home respite. For this sizable proportion of respite users, respite appears to be a last stop on the road to placement (Gottlieb & Johnson, 2000; Brody et al., 1989). This pattern of use raises the issue of whether respite is serving caregivers in a timely fashion. Among the possible factors associated with this pattern of service use are:

- Respite services may not be viewed by caregivers as appropriate for people with mild levels of impairment.
- Marketing of respite to reach caregivers earlier may be inadequate.
- Caregivers may not perceive a need for respite for themselves or their relative until late in the process.
- Caregivers may need better education so that they use services in a more timely way.

One critical factor related to utilization is cost. Caregivers may try to conserve their resources, especially if they foresee the expense of institutional care. Younger cohorts which have paid for child care may also be more willing to pay for respite services. In countries where the cost of community-based services is heavily subsidized by the government and is affordable, rates of use are, not surprisingly, higher than in the United States (Zarit & Shea, 2001). Related to cost is the issue of whether families understand or know how to utilize complex capitation and subsidy rules. These rules are often very complex for caregivers to understand. Moreover, they are often sufficiently stringent or even stingy as to have an effect opposite to what was intended; that is, rather than encouraging use, the rules lead people to conserve benefits and hold off using respite in case they need it more in the future. Low benefits may also prevent use of respite at what might be therapeutic levels.

A third conclusion from this review is that case management alone does not lead to increased use of respite services. The negative or minimal findings of the effects of respite are partly due to the fact that some of the major studies have linked people to respite services using case management, with the result that rates of use were relatively low in the treatment group, sometimes not differing from the control group. These studies call into question the efficacy of case management in its typical form in linking people to respite services. There is a need for



new approaches that improve utilization by caregivers of appropriate services. Some approaches could involve:

- Use of more generous and flexible financial incentives.
- Conduct care management over a longer period of time, giving caregivers the opportunity to explore the practical and emotional consequences of using respite as well as develop trust in the care manager.
- Ensure that case managers and families have access to high quality respite programs. Services that are of poor quality or that are not provided in a user-friendly manner could account for low rates of use.

Another consideration is that some of the caregivers in these studies may not have been appropriate candidates at that time for using respite. Data are not typically presented on the number of times respite was recommended but the caregiver refused or did not follow through. To evaluate a service properly, people must be willing to try it, and that was not necessarily the situation in the demonstrations using case management.

Fourth, the available evidence suggests that respite services have little or no effect on placement. The possibility of realizing cost-savings by delaying placement may be a chimera. In part, that is because the present method of financing long-term care in the United States probably already delays placement. Rates of placement in the United States are low compared to the European countries and Canada. The main effect of respite may be to relieve some portion of the strain on caregivers so that providing care does not take as heavy a toll. This effect can be seen in the reduction of stress and improved well being found in many studies. Caregivers' health may also be preserved, though data have not been presented on that issue.

It may also be that some caregivers use respite services to delay placement and others do not, with the result that these contrary trends cancel each other out. Employed adult children caring for a parent may be able to keep a parent with dementia at home longer by using ADS (Zarit et al., 1999). Spouse caregivers, by comparison, may use ADS only in the later stages of the illness where home care has become precarious. Not having the person at home a couple of days a week may not be enough at that point to make a difference. Further, use of ADS or other respite services may be more difficult emotionally for a spouse, and they may not get the same relief as other caregivers.

One factor missing in the various studies that have used respite or other services to try to reduce placement is true coordination of a full range of services. Offering people one type of respite (ADS, in-home, overnight) might not be sufficient. A family might be using ADS, but have difficulty getting the care recipient ready in the morning or have need for care on the weekend when the ADS is closed. It would be interesting to test a project that guaranteed service when caregivers needed it, whatever the service might be and whenever it was needed. If service were driven by caregivers' needs, caregivers might feel that they could regain control over their situation when the stress on them begins to get out of hand. This type of approach would involve considerable flexibility on the part of the service agency to meet needs on short notice, and to be flexible to the caregiver's schedule.

Fifth, there has been little focus on the costs or cost-effectiveness of services. The finding that respite has had little impact on institutionalization reduces the likelihood of cost-savings in that area. There is potential for cost-savings in other areas, for example, if respite users reduce expenditures for acute medical care, but that remains to be determined. It may be difficult to argue that respite services can be justified solely based on offsetting some other costs, especially since it is clear that there needs to be sufficient amounts of respite to be effective in relieving caregiver strain. On the other hand, the cost-effectiveness of relieving caregiver strain or depression may be reasonable, and there may be cost-savings in reduced medical use or morbidity among caregivers. More careful study of these issues needs to be done.

Sixth, very little is known about the benefits of respite services to the elder care recipient. Although the available evidence suggests positive effects, more definitive studies are needed. It may be that respite would be more acceptable to some caregivers if they understood that it is for the benefit of both the care receiver and the caregiver. Obtaining this perspective of respite coincides with other trends that may affect respite use. Notably, there is an emphasis on early diagnosis of Alzheimer's disease. Adult day service programs specifically designed for early, mild dementia may be one way of helping people maintain functional competencies for as long as possible. This type of early intervention also has the advantage of linking caregivers and patients to the service system early in the disease process, so that respite use is a familiar part of the care routine. Caregivers who later on might be reluctant to use respite would hear that it is acceptable to their relatives, and, indeed, that it is enjoyable.

Seventh, there is yet to be a trial in which respite is integrated into a comprehensive approach to assisting caregivers and their relatives. The successful trials that combined individual and family counseling (Mittelman et al., 1993; 1995; Whitlatch, Zarit & von Eye, 1991) had as one goal helping caregivers use appropriate respite services. Neither study, however, reported actual rates of use and its consequences. Given the multidimensional aspects of caregiver stress, a comprehensive approach that integrates biomedical, psychosocial and respite interventions would be very promising. This type of approach is not likely to develop naturally, given the historic barriers between medical and other services and the fragmented funding streams for psychosocial and respite services.

## **PRACTICE IMPLICATIONS FOR THE AGING NETWORK**

It should be clear from this review that controlled studies on respite are limited and that many important questions have not been addressed. Despite the limitations of current evidence, some recommendations can be made:

1. Respite services can provide critical relief for caregivers, but only when provided in sufficient amounts.
2. There are often practical barriers to obtaining respite that discourage families or limit the amount of service they are willing to use. These barriers include unnecessarily bureaucratic rules for assigning families a respite worker, a service delivery time, or for determining financial assistance. A user-friendly system in which the consumer has control over the process may lead to improved utilization (Feinberg & Ellano, 2000).

3. Respite agencies should regularly submit their procedures to a consumer board for review to identify problems and make the process more consistently user-friendly.
4. There needs to be better outreach to educate caregivers and the general public about the value of respite. This can be done in conjunction with voluntary organizations (e.g., the Alzheimer's Association).
5. Case management models may need to be enhanced so that managers have more skill in helping families understand the uses of respite and more resources to facilitate use of high quality respite.
6. Alternatively, states or other funding agencies could provide subsidies, with a minimum of red tape, directly to respite agencies, such as has been done in New Jersey (Greene & Feinberg, 1999).
7. Efforts should be made to coordinate different types of respite services (ADS, in-home, overnight) so that caregivers can readily put together a package of services if they need it. While this type of coordination is possible in theory, an honest examination of the process would probably reveal many obstacles so that only persistent and skilled caregivers can manage the system. (or as Homer Simpson once said, "In theory, communism works. In theory.").

As a final comment, I would like to encourage respite programs and their funding agencies to partner with researchers to build a better foundation of practice knowledge. This knowledge can lead to better practice and to more persuasive arguments that respite services should be reimbursed. While there are potential obstacles in collaborations of practice and research, these can be overcome. Among the more pressing issues that I believe should be studied are:

1. What are the benefits of adequate amounts of in-home respite?
2. What are the barriers that families perceive and/or encounter in the use of respite services?
3. What are the benefits and drawbacks to older clients of respite services?
4. What are the benefits and drawbacks of overnight respite for caregivers and clients?
5. Do respite services delay institutionalization under some circumstances? Keep in mind that services would need to be flexible and provided in sufficient amounts.

It is often particularly timely to study an innovative program or intervention early in its development. There are more opportunities at that time for obtaining an appropriate control group and for addressing critical questions that could lead to improvements in the program before procedures become entrenched, as well as to the dissemination of positive features. Many innovative programs have been reported over the years, only to disappear. Careful evaluation of creative approaches to respite care could help these programs achieve a more lasting impact.

## Author Description

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## RESOURCES ON CAREGIVING ISSUES

Alzheimer's Association

<http://www.alz.org>

This site provides a range of information from current research findings to identifying local resources through the Alzheimer's Association chapter network.

Alzheimer's Disease Education and Referral Center of the National Institute on Aging

<http://www.alzheimers.org/>

This site provides up-to-date information on current federal research on Alzheimer's disease and related disorders as well as links to federally-funded Alzheimer's Research Centers. There is also information specifically on caregiver issues.

Family Caregiver Alliance

<http://www.caregiver.org/>

This organization heads a statewide network of Caregiver Resource Centers in California. The web site has a rich base of information on a wide range of topics for caregivers. Much of the information would be useful to a national audience.

Caregivers PA

<http://caregiverpa.psu.edu>

This site, while focused on resources available in Pennsylvania, also contains information that would be useful to caregivers living in other states. The links to other caregiving web sites is particularly useful.

### ***Other Resources:***

A special issue of the journal, *Aging and Mental Health* (v. 5, May, 2001, supplement), provides a comprehensive review of social and behavioral aspects of Alzheimer's disease. Chapters give an in-depth analysis of interventions for caregivers, incorporating the perspective of the patient in services and research, use of technology and environmental design in dementia, and public policy.